JOURNAL OF CLINICAL RESEARCH BEST PRACTICES

Vol. 3, No. 12, December 2007 "Can You Handle the Truth?"

"The Gift of Participation: A guide to Making Informed Decisions About Volunteering for a Clinical Trial"

Kenneth Getz, 2007, 360 pages, Jerian Publishing, $19.95

Review by Norman M. Goldfarb

"The Gift of Participation: A guide to Making Informed Decisions About Volunteering for a Clinical Trial" is a comprehensive handbook for potential clinical trial subjects and their caregivers. It is also an excellent primer for novice clinical research professionals. At 238 pages plus appendices, it contains more information than most study subjects think they want to know about clinical research, but they should read it anyway. Your grandparents can probably understand the straightforward language in the book. If they can't, they probably will not understand the language in the informed consent form. Well-informed study subjects are more likely to stay in studies and adhere to study requirements, so keep a copy handy to loan them. At $19.95 a copy, you can give them out feely; in appreciation, your study subjects might even refer some friends to your study.

This book has been selected for

The First Clinical Research Bookshelf

Essential reading for clinical research professionals

The title of the book is drawn from the author's leadership in generating appreciation for the gift that study subjects give society by donating their time, comfort and potentially their health when they participate in clinical trials. When we enroll a study subject, we owe them more than competence, regulatory compliance, and good ethics; they also deserve our respect, consideration and gratitude.

To help bridge the communication gap between the clinical research enterprise and the public, Mr. Getz founded and chairs the non-profit organization CISCRP, the Center for Information & Study on Clinical Research Participation (http://www.ciscrp.org/).

The book includes 12 chapters:

- Recognizing the Gift of Participation
- Why Clinical Trials are Conducted
- Why People Choose to Participate
- A Very Human Enterprise
- Education Before Participation: Do Your Homework
- Where to Find Clinical Trials
- Giving Your Informed Consent
- Clinical Trial Care and Compensation
- A Closer Look at IRBs
- Historical Events the Have Shaped Human Subject Protection
- Considerations for Special Populations
- What to Do When Things Go Wrong

The book includes a list of 63 questions that potential study subjects should ask before signing an informed consent form. Study personnel should know the answers to these questions even if the subjects do not ask them; this list alone is worth the price of admission.

The book is available at http://www.amazon.com.

Reviewer

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